

27 April 2011

ATTENTION: Roberta Bausch
Australian Productivity Commission
GPO Box 1428 CANBERRA CITY ACT 2601,

Enquiry into Disability Care and Support

Dear Ms Bausch and committee members

My name is Michele Thredgold. I am totally blind and reside in South Australia. I am writing to express various concerns I have with the proposed recommendations for the National Disability Insurance Scheme (NDIS). Although I am a member of the South Australian branch of Blind Citizens Australia (BCA), I am writing this letter on behalf of myself, not BCA or any other disability group.

Initially I have welcomed the introduction of an NDIS as an alternative means for disability services, since services for people with disabilities here in SA leave a lot to be desired right across the board. However, upon reading a summary from the report sent out two months ago, I became deeply concerned about various points and how they will affect blind and vision impaired Australians.

My main concern has to do with statistics and figures. I believe that the statistics cited for the number of people with a disability in Australia are incorrect. While I do not have access to the correct figures myself, I do know that there are many more cases than has been cited in the report. This means that it is quite probable that far more people will be wanting to utilize the funding provided by the NDIS. This will therefore also mean that less funding will be available to each person, meaning less services.

My second concern is linked to the first. No round figure was given in regards to the amount of funding individuals will receive per annum. When discussing this at a tele-conference set up by BCA, we set a round figure of \$1200 per client. We then discussed the services which that money could be used for in one year. The conclusion was that the expectations of how far that funding would stretch was very naive. The training of a guide dog alone costs between 25-and \$30'000. This means that if I need to have a new guide dog, I would use up my annual 12'000 for possibly three years in one hit. This would therefore mean that I would not be able to pay for services such as cleaning, cooking, equipment and transport for that three years. Payment for these services would all need to come out of my pension.

Employment is very difficult to come by in SA if you are blind. I also have additional medical problems -- fibromyalgia, epilepsy and clinical depression. These conditions often leave me very fatigued and at times I have concentration problems. This means that employment for me is difficult, since many jobs would possibly be too draining without quite a lot of extra support. I am a professional singer but gigs are also difficult to come by. Therefore paying for such

services out of my pension would seriously eat into my budget. If I chose to go with the option of using the brokerage service rather than self-managed funding, this will eat into my budget even more.

The affects of my extra medical conditions also means that services to assist with cooking and cleaning especially are vital for me. Orientation and mobility is also essential from time to time and again, I would forfeit that service for three years if I needed a new guide dog.

It is my opinion, therefore, that not enough attention has been paid to the needs of blind and vision impaired Australians. I am aware this is only the initial stage of planning for the final model of the NDIS. However, if it is going to benefit blind and vision impaired people, their needs must be taken into account when the final draft of the policy is being written. Blind people will not want to pay an excess fee, either to join or annually, if services are going to fall short or if they end up missing out on essential services because the figures for funding were not accurate when the policy was drafted. History has shown that many great ideas ended up costing far more than was first envisioned, thus draining the tax-payer or the national budget. At other times, great ideas have been tossed out of parliament for the same reason. This is why, as a blind person who will be one of the Ndis recipients, I am extremely anxious to see that the PC gets this right before introducing it to parliament.

My last concern is related to the assessment stage. My experience with blindness organizations in the past has been such that often, in spite of professional ethics, personal feelings often get in the way and thus some people are extremely disadvantaged when requesting services. My question for the PC therefore is who will be determining the amount of funding provided and how the services will be utilized for each individual in this initial stage? A social worker, for example, may understand how the system works, but they will have no idea of which piece of adaptive technology will best suit each individual. Some blind people work better using Braille, for example, whilst others are happy with speech software. Braille displays, notetakers and software are far more expensive than speech software. However I work much better with Braille with speech software to enhance it, than speech alone. The specialists cited in the report, would thus need to be chosen very carefully to ensure that:

- 1 they do not know the client they are assessing, thus avoiding either favouritism or its opposite
- 2 They have a complete understanding of the needs of the client concerned, even if this means more than specialist seeing each client in the initial assessment stage.

Finally, I cannot stress enough that, each one of us is an individual with individual needs and methods of coping. What suits one person with a disability may not suit another with the same disability. One blind person may be far more independent than another but there may underlying factors such as mental illness or other medical conditions which require far more support. I myself have only three hours a week for everything I need assistance with and it is not nearly enough. My parents also come up and provide two hours of support but they are both getting old and their health is poor. I am therefore very concerned about what will happen when they die, if this current NDIS model is released to parliament.

I apologize for the length of this letter and for my frank manner. It is my sincere hope that a NDIS model can be shaped to support the needs of everyone concerned. After all, according to a

friend who lived in England for a time, the NDIS worked very well.

Best wishes for the formation of this scheme.

Yours sincerely

Michele Thredgold